

Assessing Needs: Quick Definitions and Descriptions for Data-Related Terms and Concepts Used by Ryan White HIV/AIDS Program (RWHAP) Planning Bodies¹

Terms related to Epidemiologic Data

- **Population:** The total group to be studied. For example: All the people living with HIV/AIDS in a particular State, Ryan White HIV/AIDS Program (RWHAP) Part A Eligible Metropolitan Area (EMA) or Transitional Grant Area (TGA) or other geographic area
- **Subpopulation:** A defined set of people from the group being studied. For example: HIV-positive men having sex with men (MSM) living in the MetroArea TGA
- **Percentage:** Proportion of a whole, expressed as parts in 100. For example: 10 out of 200 PLWH in the State who are using child care = $(10 / 200) \times 100 = 5\%$.
- **Incidence:** The number of new cases of a disease in a population during a defined period of time – such as the number of new HIV cases in the MetroArea TGA that were reported in 2016.
- **Incidence rate:** The frequency of new cases of a disease that occur per unit of population during a defined period of time – such as the rate of new cases per 100,000 population in your State during 2016.
- **Prevalence:** The total number of people (living or dead) in a defined population diagnosed with a specific disease or condition as of a given date – such as the total number of people diagnosed with HIV disease in your EMA as of December 31, 2016. Often the term used is “total living cases,” which means the number of people diagnosed and living with the disease as of a specific date.
- **Prevalence rate:** The total or cumulative number of cases of a disease per unit of population as of a defined date – such as the rate of AIDS cases per 100,000 population diagnosed through December 31, 2016 in the MetroArea TGA.

Needs Assessment Components

Needs assessment: A systematic process used to collect and analyze information about the number, characteristics, and needs of people living with HIV/AIDS (PLWH) in and out of care, identify current resources available to meet those needs, and determine unmet needs and service gaps. A RWHAP Part A needs assessment, as described in the *RWHAP Part A Manual* (2013) includes the following components, defined and described below:

¹ Some of the material included here comes originally from Ryan White HIV/AIDS Program (RWHAP) manuals, such as the *RWHAP Part A Manual* and *Needs Assessment Guide*. The Definitions were prepared by Emily Gantz McKay. Some of the material comes from or is revised from the Participant Manual developed by John Snow, Inc. (JSI) for the 2004 RWHAP Part A Planning Council training called “Increasing Consumer Involvement.” Emily Gantz McKay, then of Mosaica, served on the training team for those sessions. This summary document was updated by EGM Consulting, LLC in August 2016 for use at the 2016 National Ryan White Conference on HIV Care and Treatment.

- **Epidemiologic profile:** Information on the number and characteristics of people in a specified geographic area who have been diagnosed with HIV/AIDS.
- **Assessment of service needs and gaps:** Information about the service needs of people with HIV/AIDS and barriers to obtaining these services.
- **Resource inventory:** A listing and description of the providers of HIV-related services in a specified geographic area, what types of services they provide, where, and to whom – including both RWHAP and non-RWHAP funded providers.
- **Profile of provider capacity and capability:** Information on the capacity of service providers in a specified geographic area to meet the needs of people with HIV/AIDS, including the extent to which services are available, accessible, and appropriate to PLWH overall and to specific population groups.
- **Estimate and assessment of unmet need:** An *estimate* of unmet need is the estimated number of people in a specific geographic area who know they are HIV-positive but are not receiving regular HIV-related primary medical care. Now that the HIV Care Continuum is being used, a rough estimate of unmet need is the number of individuals living with HIV in a specific geographic area minus the number who are retained in care as of a specific date (e.g., December 31, 2016). An *assessment* of unmet need is information about people who know they are HIV-positive but are not receiving regular HIV-related primary medical care, including their characteristics, where they live within the State, EMA, or TGA, their primary care needs, barriers that keep them out of care, and other service gaps.
- **Estimate and assessment of HIV-positive individuals who are unaware of their status:** An *estimate* of the number of people in a specific geographic area who are HIV-positive but have not been diagnosed is usually done by using the national estimate of HIV+/unaware from the Centers for Disease Control and Prevention (CDC). That estimate has gone from more than 21% in 2006 to 13% at the end of 2013.² An *assessment* involves exploring what subpopulations (defined by characteristics such as race/ethnicity, age, gender at birth, and place of residence) are most likely to be unaware of their status. Since by definition, people unaware of their status cannot identify themselves, the assessment looks at “surrogate” (substitute) measures such as populations with late testing (people diagnosed with AIDS at the same time as or within one year after first HIV diagnosis) and trends in new diagnoses.
- **Assessment of service gaps:** A review of the population with HIV/AIDS, their identified service needs and barriers, provider capacity and capability, and often other data such as service utilization, to determine gaps in care by service category and location, and for specific subpopulations.

Terms Related to Unmet Need

- **Unmet need:** The identified need for HIV-related primary medical care among individuals in a specified geographic area who know they are HIV-positive but are not receiving such medical care – such as the number of PLWH in your State, EMA, or TGA who know they are

² See HIV/AIDS: Basic Statistics, CDC website, <https://www.cdc.gov/hiv/basics/statistics.html>

HIV-positive but are not receiving HIV-related primary medical care. The HIV/AIDS Bureau (HAB) has several ways to determining how many people within a jurisdiction have an unmet need for care or are “out of care.”

- One involves determining the number of diagnosed PLWH for whom there is no evidence of any of the following in a recent 12-month period: a CD4 count, a viral load test, or provision of antiretroviral therapy (ART).
 - The second, newer approach is based on the HIV Care Continuum; it says that a person has unmet need if s/he has not been “retained in care” as shown in the HIV Care Continuum. “Retained in Care” is the number of diagnosed individuals who had two or more documented medical visits, Viral Load or CD4 tests performed at least three months apart in a defined calendar year. Using this definition, a PLWH has unmet need if s/he did not meet the “retained in care” definition.
- **Service gaps:** The identified unfulfilled need for HIV/AIDS related services other than primary medical care among diagnosed PLWH in a specified geographic area. This term is used to avoid confusion with the HAB definition of “unmet need” as referring to primary medical care.

Types of Data Collected in Needs Assessments

- **Quantitative data:** Information that can be expressed in numbers, counted, or compared on a scale – such as epi data or aggregated PLWH survey data.
- **Qualitative data:** Information that cannot easily be measured or expressed in numbers – such as narrative data from a focus group or consumer Town Hall meeting.
- **Utilization data:** Information about the use of RWHAP services by service category; includes percent of total contract funds used by month and for an entire program year, number and characteristics of clients, overall and sometimes by type of service within the service category – for example, physician visits, laboratory tests. Provided by the Recipient or administrative agency, often based on Ryan White Service Report (RSR) data reports.
- **Unit and client cost data:** Information on the cost of providing a RWHAP-funded service, usually stated as the cost per client, cost per client per year, or cost per service unit – for example, the cost of one physician visit lasting 15 minutes or one medical case management visit lasting 30 minutes. Provided by the Recipient or administrative agency.
- **Other funding streams:** Information about funds available for HIV-related services in a specified geographic area from sources other than the Ryan White HIV/AIDS Treatment Extension Act – such as funds available for medications through Medicaid, funds for substance abuse treatment and mental health services provided by the Substance Abuse and Mental Health Services Administration (SAMHSA), or state or local funding. May be collected by the planning body staff or Recipient.

Terms Used in Analyzing Needs Assessment Data

- **Geographic disparities:** Differences in service access to appropriate services based on where an individual lives – such as differences in access to primary medical care or mental health services for people living in a rural community or outlying county.
- **Availability of services:** The level or number of “slots” within a service category that exist in a specified geographic area – such as the total number of funded outpatient substance abuse treatment slots for PLWH within a state, EMA, or TGA.
- **Accessibility of services:** The extent to which services in a particular geographic area can be obtained conveniently by people who need them – for example, whether the location of services enables PLWH to get to the facility, whether the provider offers services at appropriate hours (e.g., during the day, in the evening, and on weekends), and whether child care services are available.
- **Appropriateness of services:** The extent to which available services meet the needs of particular groups of PLWH – for example, whether service providers have staff who speak Spanish or other languages needed by PLWH in the state, EMA, or TGA; whether providers have staff from various communities of color and knowledgeable about these cultures; whether providers are experienced with and sensitive to the needs of particular population groups such as young African American men who have sex with men or transgender PLWH.

Terms and Concepts Related to Evaluating and Interpreting Data

- **Triangulation:** The process of comparing results from different needs assessment or research studies to see whether they report similar findings and giving greater weight to findings that are reported from several different studies or sources – for example, comparing PLWH survey, focus group, and epi profile trends and finding that all three indicate a growing rate of HIV/AIDS among women and among youth 18-25.
- **Critical review or “weighing” of needs assessment data:** Critically reviewing the methods used to obtain needs assessment data in order to decide how much confidence to place in the data. This usually requires considering such factors as the following:
- **Numbers:** The number of people or sample size included in the study – for example, a focus group of 8-12 youth with HIV versus a survey of 150 youth with HIV.
- **Representativeness:** Whether the individuals included are representative of the entire HIV/AIDS population or the RWHAP Part A-eligible population – for example, a survey of 500 people might have undersampled women, people of color, homeless people, people not receiving regular primary medical care, and people with a substance abuse problem.
- **Probability sampling:** Whether the study used a probability sample, which is a sampling method designed to allow findings to be assumed to represent those of the entire population from which the sample was drawn – for example, a PLWH survey of 300 drawn from a list of all individuals in the HIV surveillance database within a particular county

versus a PLWH survey of 600 that was implemented by taking survey forms to service providers and making them available to anyone receiving services at that facility.

- **Questions:** Whether the questions asked were clear and understandable, so they were likely to generate reliable data that really measure what they were supposed to be measuring – for example, if the question about whether people were receiving regular HIV-related primary medical care asked “Are you receiving regular medical care?” versus “Have you seen a primary care physician for HIV/AIDS-related care within the past year?” or “Have you received a CD4 count, a viral load test, and/or anti-retroviral therapy (ART) during the past 12 months?”
- **Quality control:** Evidence that the data were collected using appropriate methods and by trained individuals – for example, if the data were obtained through interviews, who were the interviewers and how were they trained? If focus groups were used, how were the participants screened and what training did the focus group facilitators have? Who developed the survey or interview guide? If interviewers were paid for completed surveys, what kinds of reviews were done to ensure that data were not made up?

What is Data? Unfolding the Mystery

[From the JSI “Increasing Consumer Involvement” Training Guide]

Many people find it difficult to understand statistical concepts and basic math. Some people may have a good foundation in these concepts, but suffer from “math anxiety,” meaning that they are uncomfortable dealing with numbers. If you don’t feel you can read and interpret statistical reports, understand graphs, or compare data about different population groups, you are not alone!

However, by developing your knowledge and capabilities in these areas, you can make a much greater contribution to the RWHAP planning process.

Most of us routinely use percentages, averages, and other statistics to make decisions. We also read tables and charts.

- When deciding whether we can afford a particular apartment, we use **ranges** and **averages**. The rent may be a fixed amount, but our “real” monthly cost depends upon the cost of utilities. By calling the local electric company, we can learn the average monthly cost of utilities for the apartment. We can also inquire about the range of costs. What was the lowest and what was the highest monthly cost during the year?
- When taking advantage of extra discount sales, we use **percentages**. For example, a jacket may be marked “25% off the already reduced price.” To find out how much it will cost, we have to calculate one-quarter of the sale price and subtract it from the reduced price to get the final price for today.
- We may decide whether we are overweight by comparing our weight with the **average** weight of women or men in our age group. In this example, we are using **statistics about the general population** to make a decision.

These examples demonstrate that many people with math anxiety really do have the knowledge to analyze and use statistics. Understanding statistics does not require knowledge of higher math. It simply requires becoming familiar with some basic concepts and applying the same kinds of logic and life experience to quantitative data as you do to other kinds of information.